Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

MAY 10, 2024

CDC's website is being modified to comply with President Trump's Executive Orders.

Strategies to Prevent Worsening of Symptoms

HIGHLIGHTS

Healthcare providers and patients should establish which symptoms are most disruptive or disabling and tailor management plans accordingly. Treatment should be directed toward the most problematic symptoms as prioritized by the patient. It is also important to incorporate strategies to prevent worsening of symptoms into initial and subsequent treatment plans.

Post-Exertional Malaise (PEM)

Post-exertional malaise (PEM) is the worsening of symptoms following even minor physical or mental exertion that would have been tolerated previously. Symptoms typically worsen 12 to 48 hours after activity. PEM can last for days or even weeks.

PEM can be mitigated by activity management (pacing). The goal is to avoid PEM flare-ups and illness relapses by balancing rest and activity.

Patients need to determine their **individual limits** for mental and physical activity. Then, they can plan activity and rest to stay within these limits. Some patients and healthcare providers refer to staying within these limits as staying within the "**energy envelope.**"

Limitations may be different for each patient. Keeping individual activity and symptom diaries may help patients identify their personal limitations, especially early in clinical care.

Healthcare providers need to be aware that their patients' ability to function may seriously deteriorate if they exceed their individual capacities. In general, patients should not push themselves beyond their capacities as this may exacerbate their symptoms and trigger PEM.

When patients improve, activities can be cautiously increased with monitoring for any negative effects. Patients need to be advised about "push and crash" cycles. This occurs when patients try to do too much on a "good day" to make up for "lost time." This pushing can lead to relapse.

Activity planning

Any activity or exercise plan for people with ME/CFS needs to be carefully designed based on the individual patient's presentation. Planning should take into account the patient's input.

If possible, evaluation by a rehabilitation specialist may be beneficial. For some patients, even daily chores and activities such as cleaning, cooking, or showering can be difficult. These tasks may need to be broken down into shorter, less strenuous pieces.

While vigorous aerobic exercise can be beneficial for many chronic illnesses, patients with ME/CFS **cannot tolerate** such exercise routines. Standard exercise recommendations for healthy people can substantially harm patients with ME/CFS.

It is important that patients with ME/CFS maintain activities they can tolerate since deconditioning is also harmful. For some patients, it might be necessary to treat orthostatic intolerance first. Improving patients' capacities to tolerate being upright should be accomplished before any activity can be considered for careful implementation.

Patients who can tolerate their current activity level and know how to "listen to their bodies" might benefit from carefully increasing exercise. This may help them improve their physical fitness and avoid deconditioning.

Some healthcare providers with expertise in ME/CFS refer their patients to an exercise physiologist who understands ME/CFS. These providers should use an individualized and flexible approach to advancing activity levels.

All patients are unique

Patients with ME/CFS differ in their response to symptoms and therapies. Any plans to help someone manage their illness need to be tailored to their individual abilities.

If exercise plans are not designed and executed carefully, patients may experience setbacks and serious deterioration in function and health. Expectations need to be managed, as exercise is not a cure.

However, improved function is a long-term goal of managing ME/CFS. Tolerance of aerobic exercise and normal activity levels is also a long-term goal but it should be pursued cautiously.

Activity planning for children

For some pediatric patients with ME/CFS, activities of daily living, education, and social engagement can result in PEM. Other pediatric patients with ME/CFS might sometimes be able to tolerate such activities with careful planning.

A particularly important aspect of illness management is to help children with ME/CFS continue school and stay connected with friends. Healthcare providers can work with young patients and school administrators. Tools like a study plan or an Individualized Educational Plan (IEP) may help.

Healthcare providers can play critical roles in ensuring that schools provide optimal support for students with ME/CFS. This support needs to begin while children are being evaluated for ME/CFS.

Some children with extreme fatigue and cognitive dysfunction might need accommodations such as part-time schooling or home tutoring. The occasional patient might need to withdraw from school until symptoms have improved enough to tolerate part-time classwork. For additional helpful tips on this process, see Pediatric ME/CFS Fact Sheet for Healthcare Professionals.

Orthostatic Intolerance

Many patients with ME/CFS also experience triggering or worsening of symptoms when moving to and/or maintaining an upright posture. This is known as **orthostatic intolerance**.

Symptoms of orthostatic intolerance can include frequent dizziness and light-headedness, palpitations, and feeling faint. Adolescents are particularly affected by this manifestation. As patients may not recognize that they have orthostatic intolerance, it can be helpful to ask questions such as:

- How do you feel when standing still for more than 1-2 minutes?
- What happens after you get up rapidly from sitting for a long time?
- How long can you stand before feeling ill? For example,
  - Can you do the dishes?
  - Can you stand in a line for a bus or movie?
  - Are you able to shop for more than a few minutes?
  - Can you take a hot shower/bath without feeling tired and lightheaded?

Direct measures of OI can be obtained with a relatively simple standing test, such as the NASA lean test. A formal tilt table test may be considered.

These tests are not required for diagnosis but will identify patients with an abnormal response to standing. One response may be increased heart rate (postural orthostatic tachycardia syndrome or POTS). Another possible response is low or high blood pressure (known as orthostatic hypo- or hypertension). Patients with symptoms of orthostatic intolerance can benefit from evaluation by a cardiologist and/or neurologist.

Strategies to address orthostatic problems include avoiding things that aggravate symptoms like hot environments or prolonged standing. Postural counter-maneuvers and compression or cooling garments can also be considered. If patients have inadequate salt and fluid intake, increasing both may help in some patients. Conditions for which such strategy is contraindicated include those who have hypertension, renal failure or congestive heart failure.

If non-pharmacological measures do not help, prescription medications for POTS and neurally mediated hypotension (NMH) may be needed. Prescription-strength support stockings can also be helpful.

Sleep Problems

Patients with ME/CFS have non-restorative sleep and wake up less refreshed than they did before becoming ill.

Common sleep complaints in patients with ME/CFS include:

- Frequent awakening
- Intense and vivid dreaming
- Restless legs
- Nocturnal myoclonus (night-time muscular spasm)
- Awakening unrefreshed.

Some patients with ME/CFS also experience difficulty falling asleep and hypersomnia (extreme sleepiness).

When patients follow good sleep hygiene techniques but are still waking unrefreshed, sleep medication might be indicated. Initial medications to consider are over-the-counter sleep products. If this does not improve sleep quality, healthcare providers may prescribe medication for sleep. Medication should start at the smallest dose and be used for the shortest possible time.

Patients can still have unrefreshing sleep even though they achieve required hours of sleep with medications. If possible, a sleep specialist may evaluate patients whose sleep remains non-restorative following standard interventions. It is very important for healthcare providers to get a careful sleep history and recommend a sleep study if indicated.

People with a primary sleep disorder such as sleep apnea or narcolepsy may benefit from treatment. However, if the person also has ME/CFS, they will likely still have ME/CFS symptoms after treatment of the sleep disorder.

Some patients with ME/CFS are affected so severely that standard sleep recommendations are not sufficiently helpful or might have limited applicability.

Pain

People with ME/CFS often experience deep pain in their muscles and joints. Patients may also complain of headaches (typically pressure-like or migraine-like) and sensitivity of their skin when touched.

Over-the-counter pain relievers, like acetaminophen, aspirin, or ibuprofen, can be considered first. If these do not provide enough pain relief, evaluation by a pain specialist may be indicated. As for any patient with chronic pain, counseling for pain management techniques is advisable and can be helpful.

Other non-pharmacological pain management methods can also be beneficial to some patients with ME/CFS, including:

- Stretching and movement therapies
- Manual physical therapy
- Gentle massage
- Heat
- Toning Exercises
- Hydrotherapy

Physical methods such as stretching might be helpful but require careful consideration to avoid post-exertional malaise. Acupuncture, when done by a licensed practitioner, might help with pain for some patients.

Memory and Concentration Problems

For some patients with ME/CFS, memory problems might be managed to some extent by using memory aids. These can include organizers or portable notebooks to record information, like to-do lists, appointments, and people's names. Electronic devices such as smartphones and tablets can offer an additional bonus of setting reminders for medications and appointments.

As with physical activity, patients should employ careful planning and monitoring of cognitive activities to avoid mental overexertion (post-exertional malaise). Planning periods of rest after any anticipated mental activity is critical to avoid exacerbation of symptoms. Some patients may need to avoid highly stimulating activities based on their individual capacities.

Caution is warranted in prescribing stimulants for cognitive problems. Mild stimulants may be helpful for some patients. But stronger stimulants can lead to a relapse as patients may attempt to do too much when they feel better. This is the so-called "push-crash cycle." Patients do too much, then crash, rest, start to feel a little better, do too much once again.

Patients need to be followed carefully to monitor for insomnia, weight loss, and other adverse effects. Many stimulants can be habit forming, and tolerance may develop if used daily.

Depression and Anxiety

Patients with chronic illnesses sometimes develop depression and/or anxiety as a co-morbid condition with their chronic illnesses. Some might have these conditions preceding, but not causative of, their chronic illnesses.

As many as half of patients with ME/CFS develop depression at some time during their illness. Brief psychiatric screening tools can be given and scored in the primary care setting.

When the assessments suggest possible depression or other psychiatric diagnoses, that condition should be managed. Referrals to mental health professionals may be warranted either alone or in combination with medication.

Although treating these comorbid conditions can be helpful, treatment for such conditions does not cure ME/CFS.

Some patients with ME/CFS who are clinically depressed may benefit from antidepressants. However, healthcare providers should use caution in prescribing these medications. Some drugs to treat depression might worsen other ME/CFS symptoms and cause side effects, particularly sedation and orthostatic hypotension. If prescribed, medication for depression should start at a low dose with careful monitoring for side effects. As for all patients starting anti-depressants, improvement might not occur for several weeks.

Patients with less severe ME/CFS may benefit from non-medication techniques that reduce stress and anxiety and promote a sense of well-being. Examples of such techniques include deep breathing and muscle relaxation, massage, and movement therapies (such as stretching, yoga, and tai chi).

Healthcare providers should be mindful that initiating or resuming these or other movement therapies requires careful consideration to avoid post-exertional malaise.

SOURCES

CONTENT SOURCE:
National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)

SOURCES

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